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House of Representatives

GIVE PEOPLE WITH HUNTINGTON'S DISEASE THE CARE THEY NEED!

HON. BOB FILNER

OF CALIFORNIA
IN THE HOUSE OF
REPRESENTATIVES

Madam Speaker, I rise today to recognize the month of May as National Huntington's Disease Awareness month. As some of you may know, Huntington's Disease is a genetic, neurodegenerative disease that causes total physical and mental deterioration over a 10 to 25 year period. It is a rare disease, affecting 30,000 Americans and places another 200,000 at risk of inheriting it from an affected parent. Because it is a genetic disorder, Huntington's Disease profoundly affects the lives of entire families—emotionally, socially and financially. This devastating disease has no treatment or cure and slowly diminishes an individual's ability to walk, talk, and to reason. Eventually, every person with Huntington's Disease becomes totally dependent upon others for care. In my home State of California there are more than 117,000 individuals impacted by Huntington's Disease.

Last year, Congressman Bilbray and I introduced H.R. 678, the Huntington's Disease Parity Act of 2009. This legislation does two things. First, it directs the Social Security Administration to revise and update the medical criteria for determining disability benefits for people with HD. The second part of the legislation removes the 2-year waiting period before receiving Medicare benefits. This allows individuals to receive the treatment and care they desperately need. In honor of National Huntington's Disease Awareness Month, I urge my fellow members of Congress to support H.R. 678 and help families across the Nation receive the critical benefits they need and deserve.